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# A Comparison of Elderly Participants in a Community Survey with Nonparticipants

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## Synopsis .....

*In 1982-83, 4,485 persons ages 65 or older were identified by a household census in East Boston, MA; 3,812 (85 percent) of them responded to a health and social status questionnaire. Data on age, sex, and living arrangements for the 4,485 eligible people were analyzed with respect to final participation status and reason for refusal or reluctance.*

*The health and social status of reluctant and ready self-respondents were compared, and respondents-by-proxy were compared with self-respondents. Total participation rates were similar for both sexes and all ages, but the likelihood of interview by proxy increased with age, as did the likelihood of nonparticipation due to unavailability. Living alone or with other participants favored participation, and living with refusers or other nonrespondents increased the probability of refusal. While reluctant and ready self-respondents differed in only one health variable and two social variables, respondents-by-proxy differed from self-respondents in most variables tested.*

*These analyses suggest an absence of major differences between self-respondents and refusers. Therefore, nonresponse bias is not likely to have a major impact on interpretation of the data obtained from participants in this study.*

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NOT EVERYONE ELIGIBLE participates in epidemiologic studies. Nonparticipation depends on study design and the topic under consideration (1), but it is often suspected that nonparticipants differ substantially from participants. Several studies of nonparticipants in health surveys found a higher prevalence of the disease in question, poorer health, higher mortality, or otherwise more disadvantaged status among the nonparticipants (2-11). By contrast, other researchers have observed a more favorable status for nonparticipants or little difference between respondents and nonrespondents (12-16).

Our study assessed older persons, a group not employed in previous investigations. We compared selected demographic characteristics of participants with those of nonparticipants. In addition, since available data on nonparticipants were limited, we compared people who participated only after multiple efforts to elicit their participation with those who participated

readily. We reasoned that since willingness to participate is arrayed along a continuum from eagerness to adamant refusal, the more reluctant participants would resemble people who refused to participate. Thus a comparison of willing and reluctant participants might enable us to characterize refusers better than would demographic factors alone. Several previous studies have used converted refusals, or the "hard-to-interview" group, to estimate the characteristics of refusers (17-19).

We addressed the following questions:

1. Are demographic characteristics such as age, sex, and living arrangements related to willingness to participate?
2. Do willing and reluctant participants differ with respect to the measures covered in the survey?
3. How do participants represented by proxy respondents differ from those who respond in person?

Table 1. Summary of categories of participation in survey of community residents, ages 65 or older, East Boston, MA, 1982–83

Category	Number	Percent
Participants:		
Ready.....	3,110	69
Mildly reluctant.....	161	4
More reluctant.....	394	9
Respondents-by-proxy.....	147	3
Subtotal.....	3,812	85
Nonparticipants:		
Refusers.....	566	13
Other nonrespondents.....	107	2
Subtotal.....	673	15
Total eligible.....	4,485	100

4. In the case of reluctant eligibles, is the reason given for reluctance, that is, initial refusal, related to the ultimate decision to participate or not?

Methods

**Population survey.** The East Boston study was part of a four-center project entitled, “Established Populations for Epidemiologic Studies of the Elderly” (EPESE) (20). In a 1982–83 census, interviewers visited all dwelling units in East Boston and attempted to interview every person age 65 or older. The census questionnaire covered a wide range of medical and social variables and included brief tests of cognitive function. Vigorous efforts were made to secure full participation from all age-eligible residents.

The enumerations of an estimated 99.8 percent of East Boston households revealed a population of 4,485 persons ages 65 or older. Of these, the 3,812 (85 percent) who were interviewed in person or by proxy comprise the study population. Altogether, 566 persons (13 percent) refused to take part in the survey. Eighty-three members (1.8 percent) of the elderly population died before participation or refusal could be secured, and 24 (0.5 percent) could not be contacted for other reasons (tables 1 and 2). For some analyses, these latter two groups were combined into an “other nonrespondent” category.

**Assessments of health and social status.** In the questionnaire’s self-assessment of health item (21), respondents were asked to rate their health as “Excellent,” “Good,” “Fair,” or “Poor.” Response to a question on how often the participant had difficulty holding urine until he or she could get to a toilet determined a status known as “difficulty in holding urine.” Responses were categorized as never, hardly ever or some of the time, and most or all of the time. Ability to carry out activities of daily living was measured by a modifica-

tion of the scale of Katz and coworkers (22), and functional health was assessed by items from Rosow and Breslau (23).

Immediate memory score was determined by asking participants to recount a brief, three-sentence story that was read by the interviewer. The story contained six ideas, and recall was scored on a scale of 0 to 6. Mental status was assessed by a modification of the scale of Pfeiffer (24), and depression was assessed by a modification of the CES-D scale (20, 25). All data on social status of respondents and their use of health and social services are based on self-reports.

Categories of Participation

**Participants.** Participants were divided into four categories (tables 1 and 2). Ready respondents answered the questionnaire without ever refusing, mildly reluctant respondents had refused once before participating, and more reluctant respondents had refused two or more times before participating. Participants responding through a proxy (respondents-by-proxy) were those who required another person, usually a relative, to answer most items. A proxy interview was granted only when the interviewing supervisor deemed it impossible or unlikely that the subject could be interviewed in person due to frailty or impairments. For all interviews obtained through a proxy, however, the subject was asked to respond to items requiring the judgment of the participant (for example, difficulty in performing tests that measure physical disability) and to perform the cognitive function tests. In all analyses, respondents-by-proxy were considered as a group separate from self-respondents.

**Nonparticipants.** Persons who declined to participate were classified as refusers. This category also included individuals who died before an interview could be secured if there was an indication that the person was refusing the interview. The 566 refusers composed the major category of nonparticipants. The 107 other nonrespondents were inaccessible to the interviewers. Before they could be asked for an interview, 83 of these persons had died, 4 had moved outside of the Boston area, and 20 were unavailable for other reasons, such as institutionalization or “no-contact.”

**Reason for refusal.** After every unsuccessful attempt to interview an eligible person, the interviewer recorded information about the contact, including whether other eligible people in the household participated or refused, the stated reason for refusal, and other comments, both factual and subjective. When all interviewing for the population survey had been completed, this information was reviewed. One overall reason for refusal was recorded for each refuser or reluctant participant.

Table 2. Number of persons in each category of participation in community survey of East Boston, MA, residents ages 65 or older according to sex, age, and living arrangement, 1982-83

Demographic variable	Participants				Nonparticipants		Total
	Ready	Mildly reluctant	More reluctant	Respondents-by-proxy	Refusers	Other nonrespondents	
<b>Sex:</b>							
Men .....	1,178	65	157	55	205	51	1,711
Women .....	1,932	96	237	92	361	56	2,774
Total .....	3,110	161	394	147	566	107	4,485
<b>Age:</b>							
65-69 years .....	1,209	46	154	20	216	22	1,667
70-74 years .....	871	45	93	16	161	28	1,214
75-79 years .....	542	31	77	27	103	19	799
80-84 years .....	296	24	40	25	54	15	454
85 or older .....	192	15	30	59	32	23	351
Total .....	3,110	161	394	147	566	107	4,485
<b>Living arrangement:</b>							
Alone .....	1,188	72	139	47	173	31	1,650
With others .....	1,922	89	255	100	393	76	2,835
Total .....	3,110	161	394	147	566	107	4,485

Table 3. Percentages of the eligible population in each category of participation in 1982-83 survey of East Boston, MA, community residents ages 65 or older by sex, age, and living arrangement, with proportions for each variable adjusted for the other two variables

Demographic variable	Participants				Nonparticipants	
	Ready	Mildly reluctant	More reluctant	Respondents-by-proxy	Refusers	Other nonrespondents
<b>Sex:</b>						
Men .....	69.5	3.9	9.2	3.3	11.3	2.8
Women .....	69.2	3.3	8.6	3.4	13.5	2.1
<b>Age:</b>						
65-69 years .....	72.5	2.8	9.2	1.1	12.9	1.4
70-74 years .....	71.9	3.7	7.5	1.3	13.2	2.3
75-79 years .....	67.5	4.0	9.5	3.4	13.1	2.4
80-84 years .....	63.8	5.2	8.9	5.7	12.5	3.8
85 or older .....	55.0	4.0	8.2	17.1	8.9	6.8
<b>Living arrangement:</b>						
Alone .....	72.5	4.2	8.5	2.6	10.4	1.9
With others .....	67.4	3.1	8.9	13.9	14.1	2.8

<sup>1</sup>P ≤ .01.    <sup>2</sup>P ≤ .001.    <sup>3</sup>P ≤ .05.    NOTE: In tests of significance, the ready group was the referent group, and each of the other groups was compared with it.

**Statistical analyses.** A form of the generalized Cochran-Mantel-Haenszel (CMH) test (26) was used for detection of differences among groups (tables 3-5). When ready participants were compared with the two subgroups of reluctants, the categories ready, mildly reluctant, and more reluctant were treated as ordered. In this case, when both variables were ordinal, the CMH statistic used was a stratum-adjusted correlation statistic. In table 3, tests for significance of the effects of each variable (with controlling for the other two variables) used pairwise comparisons between the ready participants (referent group) and each of the other participation categories.

To facilitate calculation of relative risk, the tabulations were collapsed to two-by-two tables. The relative

risk was estimated by the Mantel-Haenszel method (27), with adjustment for age and sex.

## Results

**Effect of sex, age, and living arrangements on participation.** The association of sex, age, and living arrangement with participation category was examined both crudely and after adjustment for the other two variables (tables 2 and 3). Sex was not associated with participation category. We found highly significant associations, however, between participation status and age (table 3). Pairwise comparisons of ready participants with each of the other categories of participation showed that older persons were more likely to be in the

Table 4. Comparison of ready, mildly reluctant, and more reluctant self-respondents in 1982–83 survey of East Boston, MA, community residents ages 65 or older

Characteristic	P <sup>1</sup>	Relative risk	
		Reluctant-ready	95 percent CI
Physical status:			
Self-assessed health . . . . .	0.61	1.03	0.93–1.15
Difficulty holding urine . . . . .	0.001	0.82	0.73–0.92
Activities of daily living . . . . .	0.53	1.04	0.86–1.25
Functional ability . . . . .	0.67	1.01	0.92–1.10
Cognitive-emotional status:			
Immediate memory score . . . . .	0.49	1.02	0.95–1.10
Mental status questionnaire . . . . .	0.33	1.09	0.91–1.31
Depression . . . . .	0.88	0.88	0.63–1.22
Social status:			
No group membership . . . . .	0.59	1.03	0.95–1.08
Attend religious service less than monthly . . . . .	0.14	1.06	0.97–1.16
See their children more than monthly . . . . .	0.53	1.10	0.96–1.26
No close friend or relative accessible . . . . .	0.03	1.32	1.00–1.73
Use of health and social services:			
Hospitalized in last year . . . . .	0.33	1.05	0.88–1.26
Ever in nursing home . . . . .	0.04	0.17	0.03–0.95
Home nursing care . . . . .	0.86	0.94	0.70–1.26
Meals and home services . . . . .	0.09	0.85	0.68–1.06
Transportation . . . . .	0.11	0.94	0.88–1.01

<sup>1</sup>Trend test, 3 groups.

mildly reluctant group ( $P = .002$ ), to be represented by a proxy respondent ( $P < .001$ ), and to have a higher risk of dying before participation or refusal (other nonrespondents,  $P < .001$ ) could be secured.

Living arrangements were a strong determinant of participation status. Persons who lived alone were more likely to be in the “ready” category and less likely to refuse than persons who lived with others ( $P < .001$ ) (table 3). Conversely, residing with others was associated with being in the respondent-by-proxy ( $P = .008$ ) or other nonrespondent ( $P = .05$ ) category. Additional age- and sex-adjusted analyses of participation status and household composition indicated that the participation status of other household residents had a major impact on the status of an eligible person. Refusers were less likely than self-respondents to live with other participants or to live alone. Furthermore, refusers were more likely to live with refusers or with other nonrespondents. All of these differences between refusers and self-respondents were highly significant.

Comparison of the living arrangements of all reluctant respondents with those of ready respondents showed that although the reluctant respondents were only marginally less likely to live with other self-respondents ( $P = .03$ ), they were much more likely to live with refusers ( $P < .001$ ) or with other nonrespondents ( $P < .001$ ). Use of the trend test to discern differences in household composition across the ready,

mildly reluctant, and more reluctant groups indicated that people who lived with refusers had the greatest likelihood of being in the more reluctant category and the least likelihood of being in the ready category ( $P < .001$ ).

### Comparison of ready and reluctant participants.

After adjustments for age and sex, we compared the ready, mildly reluctant, and more reluctant participants with regard to a number of measures (table 4). Of the 16 correlates examined, only difficulty holding urine was significantly different among the three groups. Persons who reported such difficulty were more likely ( $P = 0.001$ , trend test) to be in the ready than in either of the reluctant groups, which had a lower risk of urinary incontinence than did the ready group.

Two associations were of borderline significance in the trend tests. As compared with the ready group, the two reluctant groups combined had a lower risk ( $P = .04$ ) of ever having been in a nursing home, but a greater risk of being without a readily accessible close friend or relative ( $P = .03$ ). The reluctant participants were similar to the ready participants with regard to the other characteristics studied.

### Comparison of respondents-by-proxy with self-respondents.

Since interviews by proxy were limited to impaired eligible people unable to respond in person, it is not surprising that respondents-by-proxy reported poorer health status than self-respondents. Table 5 shows that the participants who responded through a proxy differed significantly from the self-respondents. Respondents-by-proxy were more likely to report poorer health ( $P = .001$ ), difficulty holding urine ( $P = .001$ ), and to have lower scores in the activities-of-daily-living scale (22) ( $P < .001$ ) and the functional health scale (23) ( $P < .001$ ). Of the two cognitive function tests, only the immediate memory score was significantly different between the respondents-by-proxy and the self-respondents ( $P = .007$ ), while the mental status questionnaire (24) and the depression scale (20, 25) indicated that respondents-by-proxy were slightly more likely to be impaired ( $P = .03$ ) or depressed ( $P = .05$ ).

Examination of the social characteristics of those participating through proxies revealed a number of differences. Respondents-by-proxy were less likely than self-respondents to belong to social groups ( $P = .03$ ). Respondents by proxy, however, had a greater likelihood than the self-respondents of infrequent attendance at religious services ( $P < .001$ ) and of seeing their child(ren) often ( $P < .001$ ). Use of services by the group participating through proxies also differed from that of the self-respondents. Those represented by proxies were more likely to have ever been admitted to a nursing home ( $P < .001$ ), to have used home nursing services

( $P < .001$ ), and not to have used transportation services available to the elderly ( $P < .001$ ).

**Relationship between reason for reluctance and final participation status.** Tabulation of the major reasons for reluctance to participate (among the reluctant and refuser groups) showed that the three most frequent were, in order, inconvenient time, uncooperative or disinterested, and reluctance expressed to the interviewer by another person. For all persons initially reluctant to participate, the relation of these three categories plus the reason categories "too sick" and "all other reasons" to final participation status was examined. Participants represented by proxies were excluded from this analysis. Of 51 persons with "too sick" as the reason, 41 (80.4 percent) participated; of 158 persons with "inconvenient time" as the reason for refusal, 100 (63.3 percent) participated; and of 282 in the "all other reason" category, 173 (61.4 percent) participated. In contrast, those eligible people categorized as uncooperative or disinterested were least likely to change their minds and ultimately participate; of the 368 persons in this category, only 107 (29.1 percent) participated. The participation rate of eligible people whose reluctance was expressed by another person was 44 percent (75 of 170).

## Discussion

Three observations in this study were of particular note. First, the 566 refusers, who composed the major category of nonparticipants, appear similar to self-respondents with respect to age and sex. By contrast, the 107 other nonrespondents and the 147 respondents-by-proxy were older than self-respondents and were more likely to live with others (tables 2 and 3); the association between respondent-by-proxy status and living with others may have been due to the ready availability of a household member to serve as a proxy. The fact that many other nonrespondents died soon after initial contact suggests that their health status was very different from that of participants, particularly self-respondents.

Second, age and living arrangements were highly correlated with participation. Although we had anticipated that those who lived alone might be more difficult to recruit, this was not the case. Except for respondents-by-proxy, the participation rate was higher for persons living alone than for persons who live with others. This finding led to examination of the effect of participation status of other household members on the willingness of an eligible person to respond. Subjects living with refusers or other nonrespondents were at greatly increased risk of being in the refusal, reluctant, or other nonrespondent category. Conversely, living with participants favored participation.

Table 5. Comparison of respondents-by-proxy with self-respondents in 1982-83 survey of East Boston, MA, community residents ages 65 or older

Characteristic	P	Relative risk	
		By proxy-self	95 percent CI
Physical status:			
Self-assessed health.....	0.001	1.22	1.02–1.47
Difficulty holding urine.....	0.001	1.21	1.01–1.46
Activities of daily living.....	<0.001	2.10	1.76–2.51
Functional ability.....	<0.001	1.28	1.15–1.41
Cognitive-emotional status:			
Immediate memory score....	0.007	1.27	1.07–1.51
Mental status questionnaire..	0.03	2.09	1.06–4.11
Depression.....	0.05	3.62	1.03–12.74
Social status:			
No group membership.....	0.03	1.13	1.01–1.26
Attend religious service less than monthly.....	<0.001	1.38	1.22–1.56
See their children more than monthly.....	<0.001	2.89	1.85–4.63
No close friend or relative accessible.....	0.51	1.15	0.75–1.76
Use of health and social services:			
Hospitalized in last year.....	0.05	1.31	0.99–1.72
Ever in nursing home.....	<0.001	5.48	2.81–10.69
Home nursing care.....	<0.001	1.96	1.46–2.64
Meals and home services....	0.99	0.99	0.73–1.38
Transportation.....	<0.001	0.61	0.49–0.74

In contrast to the strong effect of housemate's participation status on willingness to participate, we found no association between sex and participation rates or between age and participation rates when the percentages in all categories of self-respondents and respondents-by-proxy were combined (table 3). However, the proportion of the population who were self-respondents decreased with age, while the proportion who were mildly reluctant increased with age. Had we not offered the option of participation-by-proxy to frail and impaired persons, our participation rates would have been lower among the oldest members of the population. Our observation that participation rates for self-respondents decreased with age agrees with some previous reports (4, 28-31) but not with others (5, 10). However, in none of these studies were frail elderly people given the opportunity to respond by proxy.

Third, our analyses show that the two subgroups of persons initially reluctant to participate resemble the ready participants with respect to a number of demographic, health, and social factors (tables 3-5). Of the variables examined, we found substantial differences with regard to only three. Reluctant participants were more likely to live with refusals or with other nonrespondents and were less likely to have difficulty holding urine.

Few researchers conducting health surveys have looked at differences between ready and reluctant par-

ticipants, but an investigation of late recruits, that is, converted refusers or reluctant participants, into an urban health survey showed that late recruits were similar to the ready participants in 185 of 200 variables studied (17). In nonhealth-related sample surveys, Robins (18) and Smith (19) also found few differences between ready responders and those who resisted being interviewed. Nevertheless, as Smith pointed out, there are limitations and imponderables inherent in extrapolating from reluctant participants to refusers. We can say only that if willingness to be interviewed is spread along a continuum, there is probably overlap, and therefore common characteristics, between the reluctant participants and refusers. Such overlap is especially likely in our study because interviewers made vigorous efforts to convert refusers.

Since the response rate in our survey was high (85 percent if respondents-by-proxy are included, 82 percent if they are excluded) and since it is probable that some of the 13 percent who refused to participate resemble the reluctant participants in health and social characteristics as well as in the demographic variables, we conclude that nonresponse bias is unlikely to place major limitations on the interpretation of our data or on the data from other similar studies of the elderly. However, the nature of nonresponse does differ from one survey to another, and evaluation of the nonresponse bias must take into consideration the characteristics of the population as well as the methodology employed.

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